

Should patient groups accept money from drug companies?

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YES By accepting donations from drug companies, patient groups lay themselves open to allegations that they are losing their independence and becoming part of industry's efforts to "sell more pills." Not taking such money reduces the opportunity that patient groups have to advance their case for better services and support the individuals and families on whose behalf they speak. Damned if they do, and damned if they don't; is there a way to steer through this dilemma?

There is nothing inherently wrong with patient groups taking money from the drug industry provided that it does not put them under pressure to adopt a position that they would otherwise not choose to take up. Patient groups and industry share some common objectives, so collaboration is reasonable when these mutual interests overlap. Industry can provide core funding, funding for projects or publications, or both. Providing the source is acknowledged and there are no hidden strings, industry funding can be an important boost to the viability of patient groups—particularly as public or charitable funding often does not cover core costs.

No giving is free

The idea that public money, or grants from charitable trusts, come without strings attached is a fiction. No person or group will be overly keen to support a campaigning organisation if they think that their money will be used to "buy a stick to beat them with." Government grants often give the grant making department the control over outcomes. A Charity Commission survey of over 4000 charities delivering public services showed that only 26 "felt free to make decisions without pressure to conform to the wishes of the funders" that is, the public sector.¹

Nor is it the case that public sector bodies display higher standards of ethical conduct than private sector ones. The World Health Organization recently seemed to be trying to use a patient organisation to disguise a grant from industry to help fund a report on mental



health (although it claimed clumsy wording led to a misunderstanding).²

So why not go to the general public for support? This is an option for some, but the public is more inclined to give to causes it understands, and patient organisations (particularly if they concentrate on policy and strategic issues) may not attract instant public sympathy. Arguments about animal experimentation or the use of embryonic stem cells, for example, are difficult to communicate through sound bites to a mass audience.

Ensuring independence

Patient organisations should not take money from the drug industry if they feel that it would compromise their ability to achieve their objectives. Just as many patient groups will not accept tobacco money, or other ethically unacceptable sources of funding, so they should avoid becoming over-dependent on any one funder, whether public or private. Fashions in funding change and today's funding priority can quickly become tomorrow's lost cause. Without diversified funding, patient groups can find themselves exposed. Diversity also gives protection from the fear of undue influence being exerted. Although it may be painful to walk away from a funder, doing so will be much less of a problem if your portfolio is diversified.

Patient groups need to be principled, but they need to be pragmatic too

Although clumsy attempts have been made in the past to use money to manipulate patient groups, the Association of British Pharmaceutical Industry recently established a framework for industry funding of patient groups.^{3,4} A few simple precautions help deter inappropriate offers of help. Patient groups should ask themselves about the origins of an idea for a given project—was it their own or did a third party propose it? Do they retain control over the process and the outputs? Is there any desire to conceal the payer's identity? If financial support is out in the open and any attached strings are clear and appropriate (for example, restricted to a specific project or publication) then industry money is as good as that from any other source. Neither patient groups nor the drug industry should be shy about a relationship that has the potential to benefit not just the participants but which can also improve effective patient advocacy. Indeed, it is surprising to many working for patient groups that the drug industry is not a more vociferous champion of its relationship with patient groups. Industry funding has been an enabler for many patient groups—just as it has for clinicians and academics.

Patient groups are not naïve. They value their independence fiercely and are quite capable of spotting the strings that may be attached to funding—whatever the source. If those strings are unacceptable then most will walk away. In the experience of many patient groups, industry money often comes with fewer strings than that from other sources.

Although it can feel ideologically fine to turn your back on drug industry money, out in the real world there is a job to be done. Patient groups need to be principled, but they need to be pragmatic too. Patients demand effective advocates, and if drug company money makes this possible then bring it on. Actions that change things for the better will be welcomed by patients irrespective of the funding source. Ideological purity at the cost of preserving the status quo will and should be rejected as a cop-out.

Competing interests: AK has received honorariums from GSK and Novartis and has travelled to speak at conferences paid for by Roche, EFPIA, and Genzyme. The Genetic Interest Group has received funding from various pharmaceutical and biotechnology companies in the past year (see www.gig.org.uk/gig/docs/annualreport0506/website.pdf for list).

References are in the full version on bmj.com